Literature Review

Alzheimer's Disease Policies in OECD Countries

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Executive summary and key learnings

Alzheimer's disease (AD) and other major neuro-cognitive disorders (NCDs) pose significant challenges as the number of people living with Alzheimer's disease is rapidly increasing. Alzheimer's disease is incurable and has biopsychosocial implications for those affected. This obviously raises a multitude of issues for persons with AD and their families, but from a societal point of view, these issues require developing collective solutions by transforming communities, developing better organizational practices and adopting renewed public policies. It is in this spirit that since the early 2000s some governments have adopted action plans for these diseases.

We conducted a literature review with the objective of understanding the social dynamics that led to the adoption of public policies, identifying their main areas of action, and exploring how these measures are actually implemented. This report presents the results of the literature review in four main sections:

- **Section 1. The literature review strategy**. We used three types of documentary data: 1) 57 scientific articles that focused on the process of recognizing the social problem of AD and NCDs, the political agenda, content, implementation and effects[1]; 2) two reports published by international organizations; and 3) action plans for these diseases which have been adopted by eight of the ten Canadian provinces. We analyzed these documents using a grid based on a public policy analysis model, and the main areas of public policy as identified by the World Health Organization (WHO).

- **Section 2. How AD and NCDs came to appear on the political agenda, their emergence as a social problem and the adoption of dedicated public policies.** From 1900 to 1970, AD and NCDs were mainly perceived as a state of madness associated with old age. The boom in medical research in this area in the following decades changed the social representations and contributed to the recognition of the pathological nature. The dissociation of normal aging from cognitive disorders has contributed to the development

[1] The majority of articles focuses on the content of action plans.

of associative movements along with increased media attention. Although AD and NCDs emerged as a social problem in the second half of the 20th century, the importance of the psychosocial needs of those living with their impact was diminished in public policy and in the care provided. However, recognition of these needs has grown since the early 2000s, and many governments have adopted action plans. Several scientific articles propose that the participation of people with Alzheimer's disease, their families and the organizations that make their voices heard in the policy making process, is a particularly favourable condition for the recognition of their needs and their expertise. Governments must, however, develop mechanisms that effectively support the ability of these actors to act, rather than simply delegating responsibilities to them.

The key learnings in this section are:

- Between 1900 and 1970, Alzheimer's disease (AD) and other major neuro-cognitive disorders (NCDs) were the subject of very few social and political concerns. The medicalization of these diseases and the rise of the associative movement during the years from 1970 to 2000, contributed to their recognition as a social problem. However, psychosocial needs were sparsely addressed until around the year 2000, when these diseases became part of the political agenda.

- Since the early 2000s, 27 national governments have adopted action plans for AD and NCDs, not to mention the plans adopted by subnational governments. For example, in Canada, eight of the ten Canadian provinces have adopted action plans. The province of Ontario was the first to adopt a plan, in 1999.

- In 2017, the Canadian government passed legislation requiring the adoption of a national strategy in this area. Sustained collaboration between the federal and provincial governments will be required to avoid potential duplication.

- Several scientific articles show that the participation of civil society facilitates the development of an action plan. Seeking out and recognizing the expertise of people living with AD and their families, enables the design of public policies that are better adapted to the needs of the people concerned.

Section 3. Action plans - Comparison and identification of predominant trends. In a report by the WHO, seven main areas were identified: 1) dementia as a public health priority; 2) dementia awareness and friendliness; 3) dementia risk reduction; 4) dementia diagnosis, treatment, care and support; 5) support for dementia carers; 6) information systems for dementia; and 7) dementia research and innovation (World Health Organization, 2017). These areas transcend action plans for AD and other major NCDs, and are thus broadly convergent, although WHO recommends that governments operationalize them in concrete measures adapted to their political, sociosanitary, population and territorial realities. We observed that measures to improve early phases of the care and service trajectory, such as improved diagnosis, are the focus of the action plans. Improved diagnosis is usually put in place too late, constituting a major obstacle to the implementation of follow-up adapted for people living with the repercussions of these diseases. This explains why diagnostic measures are almost universally promoted in public policies, under various conceptual arrangements. However, several action plans have not given the same importance to the development of care and services, following diagnosis, and this can generate feelings of helplessness. A holistic approach to the needs of people living with AD and NCDs, requires public policies to reflect the same intensity in all of the main areas. This can be achieved using the concepts of dementia capable, dementia friendly and dementia positive. These shared concepts are useful in functional components, in transforming the physical and social environment, and in recognizing that people with Alzheimer's disease deserve to live a fulfilling life. This approach is key for people living with these diseases, and their loved ones, to fully exercise their remaining abilities and live with dignity.

The key learnings in this section are:

- The main areas of the various action plans are broadly convergent. The experience of other jurisdictions is very useful in inspiring interested governments to develop an action plan. Many experts and studies recommend that policymakers draw a portrait of the situation in their jurisdiction, and translate and operationalize the major normative orientations into concrete measures, adapted to their political, social, population and territorial realities.

- The measures in the action plans most widely promoted are diagnosis, workforce training, and access to care. Action in these three areas is an obvious prerequisite for implementing adapted follow-up care, yet follow-up is at times overlooked in these plans.

- Despite the fact that the psychosocial needs of people living with the repercussions of AD and NCDs are better recognized now than in the 20th century, some action plan measures focus on the cure and the biomedical model. In Canadian provincial action plans, the biopsychosocial aspects are generally well thought-out. The concepts of dementia capacity, dementia friendly and positive dementia are particularly interesting for a holistic approach that fully considers the needs of people living with these diseases.

❖ **Section 4. Policy implementation process.** The first characteristic of effective implementation of an action plan is the adequate investment of financial resources. The second determinant is the development of a national steering committee, which serves to coordinate numerous departments and partners in various levels of government involved in the implementation of change. The committee helps plan activities implemented, address issues encountered, and monitor and follow up on changes made. The third determinant is the development of a strategy to support change. Several governments have developed projects that experiment with change in practices. Projects that stand out are identified and the conditions of change and implementation are understood, with a view to scaling up. Based on learnings from the literature review, governments need to consider four major aspects when engaging in this type of strategy: 1) mobilizing local actors is crucial to rooting change in local realities; 2) change needs to be flagged and actors must be supported to fully achieve the fundamental objectives of public policy; 3) experimental projects must be rigorously evaluated to draw meaningful learning from them; and 4) large-scale dissemination of innovative practices must mobilize the same type of implementation strategy and maintain the importance of the conceptual foundations on which the experimental projects were based. The policy implementation process must be a priority for governments since the real action to effectively improve the quality of life of people living with the repercussions of AD and NCDs can be realized only by the effective implementation of the measures proposed in the action plans.

The key learnings in this section are:

- Several scientific articles reveal that implementation of an action plan is greatly facilitated if the targeted actions are precise and well-embodied in the populational particularities of the jurisdiction, and if the various stakeholders are actively involved in the realization of these projects.

- Many governments have adopted action plans on AD and NCDs, in a context of national and international mobilization, although implementation varies widely. Scientific articles identify three major measures to facilitate the implementation of action plans: 1) allocation of sufficient financial resources that are well-distributed in the action areas; 2) set up of a committee to pilot the implementation; and 3) development of implementation strategies to support changes in practice.

- Regarding implementation strategies, some governments have developed experimental projects to determine best practices and implementation conditions, followed by national dissemination of results. Scientific articles indicate four major aspects that policymakers need to take into account when undertaking this strategy: 1) the mobilization of local actors is crucial to root the changes in local realities; 2) the changes must be tagged and local actors must embody the fundamental objectives of public policy; 3) these experimental projects must be rigorously evaluated to draw meaningful learnings from them; and 4) the large-scale dissemination of innovative practices must mobilize the same implementation strategy and maintain the importance of the conceptual foundations on which the experimental projects were based.

- Two scientific articles have shown a positive influence resulting from the implementation of action plans. In England, the number of people diagnosed has increased significantly and in France, both diagnoses and the number of scientific publications have increased significantly. This makes it possible to precisely demonstrate that the anticipated effects of certain action plans translate into real effects.

- Several studies have compared the content of the action plans. To our knowledge, no study has compared the evaluation of plans between the countries of the Organization for Economic Cooperation and Development, or between Canadian provinces. Such a study would promote a better understanding of the types of evaluations mobilized by governments, the actual measures that were implemented, and the conditions which favoured their implementation.

Introduction

Alzheimer's disease (AD) and other major neuro-cognitive disorders (NCDs) pose a definite public health challenge as the number of people with these degenerative diseases is expected to increase rapidly in the coming decades. There is no scientifically recognized treatment to slow disease progression. As a result, both body and mind are dramatically transformed within a few years, posing a myriad of challenges and repercussions for people living with Alzheimer's disease, their families, their communities, caregiving organizations and governments.

Since the early 2000s, various governments have adopted action plans to address these issues. At the international level, at least 25 countries have an Alzheimer's action plan (Alzheimer's Disease International, 2018), without counting the plans adopted by subnational governments[2]. For example, in Canada, eight of the ten Canadian provinces have adopted an action plan.

The research methods used to carry out the literature review are described in Section 1[3], with the following three main objectives guiding the literature review process:

[2] Federalist systems consist of several levels of government: a central level and regional levels (e.g., provincial in Canada, state in the United States). We refer to regional levels when we use the term 'subnational'. 'Provincial plan' refers to an action plan adopted by a Canadian province.

[3] This report focuses on Canadian provincial action plans and policy studies in OECD countries. The scope of the latter varies greatly from one study to another. The reader cannot infer that a measure announced in a plan has been implemented or had the expected effect.

1) To understand the mechanisms of placing AD and NCD policies on a public agenda, by exploring their emergence as a social problem and eventual adoption as public policy (Section 2);

2) To describe the policy orientations for AD and other major NCDs in Canada as well as in OECD countries, compare them and identify major trends (Section 3);

3) To explore the policy implementation process (Section 4).

1 Methodology

The literature review draws on scientific articles and gray literature. The documents from gray literature are mainly reports published by international organizations, and AD and NCD action plans adopted in Canada. The documentation selection and analysis process is presented below.

1.1 Scientific articles

Peer-reviewed scientific articles were identified by keywords in selected databases, specific criteria, and type of publication.

1.1.1 Keywords and bibliographic databases

The search strategy consisted of three major series of keywords. The first series was related to Alzheimer's disease, the second to public policies and the third to government activities. We identified the main synonyms associated with each of the major themes (Table 1-1).

Table 1-1 – List of keywords used to identify scientific articles

	Series	Keywords
	1)	"Dementia*" OR "Alzheimer*" OR "Memory disorders" OR "Cognition disorders"
AND	2)	"Public polic*" OR "Social polic*" OR "Health polic*" OR "Public health" OR "Plan" OR "Strategies"
AND	3)	"Polic*" OR "Government*"

The three series of keywords were crossed in the following databases:

- Anglophone databases: 1) Abstracts in social gerontology; 2) Ageline; 3) CINHAL; 4) ERIC; 5) International political science abstract; 6) MedLINE with full text; 7) social work abstracts; and 8) SOC INDEX with the full text.

- Francophone databases: 1) CAIRN and 2) Érudit.

1.1.2 Criteria and three-step study selection

An initial 4,302 scientific articles were identified. The following selection criteria were applied to retain only those articles relevant to our objectives:

- Year of publication: Selected articles were published between January 2000 and February 2018 for a recent focus. All articles outside of these dates were excluded.

- Type of article: Peer-reviewed theoretical articles, empirical studies, and editorials describing public policy directions were included. Theses, books, and general opinion articles on AD and NCD public policy were excluded.

- Language of article: Only articles written in either English or French were selected, allowing for a more rigorous analysis.

- Origin of policy: Articles on governments from OECD member countries and their subnational governments were selected. In excluding non-OECD countries, the focus was kept on somewhat convergent political and economic systems.

- Themes: We retained articles that analyzed the process of recognizing AD and NCDs as a social problem, their introduction to the political agenda, content, policy implementation and effect. We also retained analysis of a specific aspect of public policy, such as the place of cultural minorities. We excluded all articles dealing with organizational policy (e.g., regulation and organizational policies of nursing homes), epidemiological studies, expert conferences on AD and NCDs, best clinical practices, as well as policy recommendations. Such studies on specialized clinical aspects are relevant to policymakers, however in this literature review the focus is on actual political experience in OECD countries.

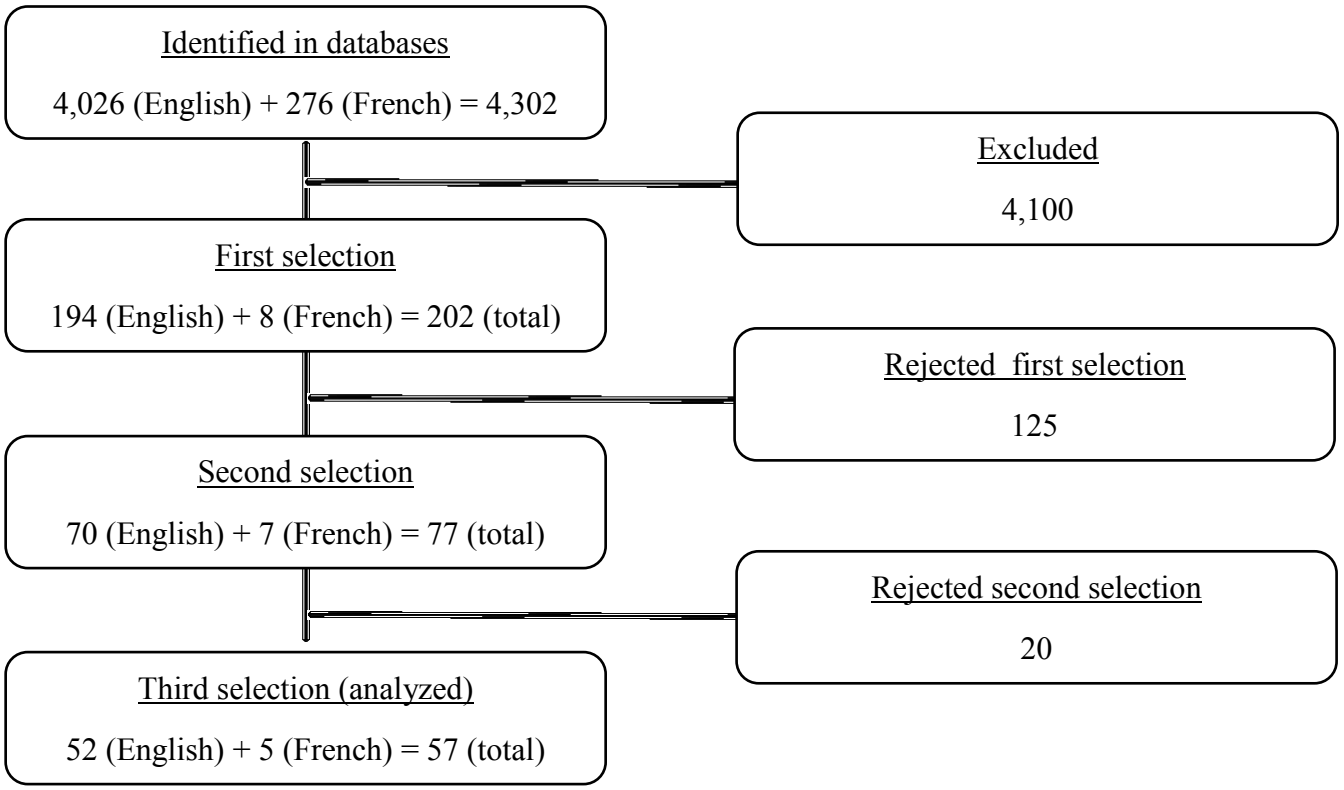
Based on the above criteria, articles were selected in three major phases (Table 1-2):

- First phase: The titles and abstracts of the 4,302 initially selected articles were scanned, of which 202 met the selection criteria and were extracted from databases.

- Second phase: We read the summaries and used speed reading techniques on the 202 articles. Seventy-seven articles met the criteria and were selected.

- Third phase: After an in-depth reading of the 77 articles, 57 fully met our selection criteria for analysis.

Table 1-2 – Three-step selection process



1.1.3 Characteristics of selected articles on Alzheimer's disease policies

1.1.3.1 Number of articles published by year

Since the early 2000s, there has been a marked increase in the number of articles on the topic of AD and NCD public policy. Between 1999 and 2008, five articles were identified; between 2009 and 2017, 60 articles on this topic were identified (Table 1-3). The increase in the last decade suggests a surge in public policy concern with respect to AD and NCDs. We examined various articles covering the public policies adopted in a number of OECD countries.

Table 1-3 – Articles analyzed by year

Year of publication of articles	Number of articles	Reference
2000		
2001	2	(Riggs, 2001; Stone, 2001)
2002		
2003		
2004		
2005		
2006		
2007	1	(Ngatcha-Ribert, 2007)
2008	2	(McDonald & Heath, 2008; Williamson, 2008)
2009	5	(Buswell *et al*., 2009; Comer, 2009; Iliffe & Wilcock, 2009; Rocher & Lavallart, 2009; Williamson, 2009)
2010	7	(Arai, Arai & Mizuno, 2010; Banerjee, 2010; Boyle, 2010; Cahill, 2010; Connelly, 2010; Greaves & Jolley, 2010; Woods, 2010)
2011	6	(Koch & Iliffe, 2011; Lucas, 2011; Lustman, 2011; O'Connell, 2011; Rosow *et al*., 2011; Truswell, 2011)
2012	4	(Chaufan *et al*., 2012; Khachaturian, Khachaturian & Thies, 2012; McCabe & Bradley, 2012; Pimouguet *et al*., 2012)
2013	1	(Innes & Manthorpe, 2013)
2014	9	(Clarke *et al*., 2014; Egge, 2014; Evans, 2014; Fortinsky & Downs, 2014; Hoffman, 2014; Mukadam *et al*., 2014; Nakanishi & Nakashima, 2014; Somme *et al*., 2014; XinQi, Ruijia, Simon, 2014)
2015	9	(Di Fiandra *et al*., 2015; Engedal, 2015; Haeffner-Cavaillon *et al*., 2015; Nakinishi *et al*., 2015; Porock *et al*., 2015; Shih-Yin & Lewis, 2015; Snyder *et al*., 2015; Travers, Lie & Martin-Khan, 2015; Williamson, 2015)
2016	6	(Ankri, 2016; Godard-Sebillotte, Vedel & Bergman, 2016; Guse, 2016; Morton-Chang *et al*., 2016; Peate, 2016; Simpson, 2016)
2017	4	(Arbogast, Welleford & Netting, 2017; Edick *et al*., 2017; Pearson, 2017; Watchman *et al*., 2017)
Début 2018	1	(Thornill & Conant, 2018)
Total	57	

1.1.3.2 Countries covered by articles

The articles analyzed focused on public policies in 14 countries (Table 1-4). The majority covered the United Kingdom (n = 20), United States (n = 11) and France (n = 8); this greater coverage is reflected in our results. The public policies of Canada were covered by four articles, those of Ireland by two. The public policies of five countries were covered by one article each: Australia, Italy, Japan, Norway, and Switzerland. Finally, seven articles focused on the public policies of several countries with comparisons between them[4].

[4] Comparisons between several countries include the United Kingdom, Australia, Canada, Denmark, Finland, France, Japan, Netherlands, Norway, Sweden and United States.

Table 1-4 – Articles analyzed by country

Country	Number of articles	Reference
United Kingdom[5]	20	(Banerjee, 2010; Boyle, 2010; Buswell *et al*., 2009; Clarke *et al*., 2014; Connelly, 2010; Evans, 2014; Greaves & Jolley, 2010; Iliffe & Wilcock, 2009; Innes & Manthorpe, 2013; Koch & Iliffe, 2011; McCabe & Bradley, 2012; McDonald & Heath, 2008; Mukadam *et al*., 2014; Pearson, 2017; Peate, 2016; Truswell, 2011; Williamson, 2008; Williamson, 2009; Williamson, 2015; Woods, 2010)
United States	11	(Arbogast, Welleford & Netting, 2017; Chaufan *et al*., 2012; Egge, 2014; Hoffman, 2014; Khachaturian, Khachaturian & Thies, 2012; Porock *et al*., 2015; Riggs, 2001; Snyder *et al*., 2015; Stone, 2001; Thornill & Conant, 2018; XinQi, Ruijia & Simon, 2014)
France	8	(Ankri, 2016; Comer, 2009; Haeffner-Cavaillon *et al*., 2015; Lustman, 2011; Ngatcha-Ribert, 2007; Pimouguet *et al*., 2012; Rocher & Lavallart, 2009; Somme *et al*., 2014)
Canada	4	(Godard-Sebillotte, Vedel & Bergman, 2016; Guse, 2016; Morton-Chang *et al*., 2016; Simpson, 2016)
Ireland	2	(Cahill, 2010; O'Connell, 2011)0
Australia	1	(Travers, Lie & Martin-Khan, 2015)
Italy	1	(Di Fiandra *et al*., 2015)
Japan	1	(Arai, Arai & Mizuno, 2010)
Norway	1	(Engedal, 2015)
Switzerland	1	(Lucas, 2011)
Comparison of many countries	7	(Edick *et al*., 2017[6]; Fortinsky & Downs, 2014[7]; Nakanishi & Nakashima, 2014[8]; Nakinishi *et al*., 2015[9]; Rosow *et al*., 2011[10]; Shih-Yin & Lewis, 2015[11]; Watchmann *et al*., 2017[12])
Total	57	

[5] References include articles on 4 action plans: England, Northern Ireland, Scotland and Wales.
[6] Comparison covers 22 action plans: countries - Australia, England, Finland, France, Ireland, Israel, Japan, Malta, New Zealand, Norway, Scotland, South Korea, Switzerland, Taiwan, United States, Wales, and; Canadian provinces - British Columbia, Manitoba, Newfoundland and Labrador, Ontario, Québec, Saskatchewan.
[7] Comparison covers 7 action plans: Australia, England, France, Netherlands, Norway, Scotland and United States.
[8] Comparison covers 8 action plans: Australia, Denmark, England, France, Japan, South Korea, Sweden and Netherlands.
[9] Comparison covers 14 action plans: Australia, England, Denmark, Finland, France, Japan, Northern Ireland, Norway, Scotland, South Korea, Sweden, the Netherlands, United States and Wales.
[10] Comparison covers 8 action plans: Australia, Canada, China, France, India, South Korea, United Kingdom, and United States.
[11] Comparison covers 14 action plans: Australia, Canada, England, Finland, France, Northern Ireland, Israel, Malta, Norway, Norway, Scotland, Netherlands, United States and Wales.
[12] Comparison of the scientific literature from the perspective of consideration of intellectual disability in action plans.

1.1.3.3 Types and subjects of articles

Of the 57 articles selected, 33 were research-based and 24 were editorials. The latter were useful in providing context.

The focus of articles relating to public policy on AD and NCDs has evolved over the decades. Those published between 2000 and 2007 present a general discussion, for example the importance of adopting policy. Since 2007, articles have become more specifically focused on the analysis of adopted AD and NCD action plans, emphasizing public policy or a comparison of public policies adopted in various jurisdictions. In 2009, articles appeared on public policy implementation. Since then, studies on policy implementation have increased. If this trend continues, the measures implemented, facilitators to implementation and their obstacles will be better understood. Our study utilized articles on action plans adopted in OECD member countries and Canadian provinces, including some articles on implementation; the scope varies greatly by country and province. It was not possible to capture all the measures formulated in action plans, or all the efforts to implement these measures.

1.2 Grey literature

Grey literature consists of publicly accessible documents, not under the purview of commercial publishers. In addition to scientific articles, our study utilized two types of

grey literature: major reports published by international organizations, and action plans adopted in Canadian provinces.

1.2.1 Major reports published by international organizations

Two recently published reports on AD and other major NCDs from the World Health Organization (WHO)[13] and Alzheimer's Disease International (ADI)[14] were selected.

1) The WHO report entitled *Global action plan on the public health response to dementia* (2017-2015) (World Health Organization, 2017) proposes recommendations for countries wishing to develop and implement action plans on AD and NCDs. Our results on action plans are based on the areas identified in this report, situating the public policies of various countries according to WHO recommendations.

2) The most recent ADI report entitled *World Alzheimer Report 2016: Improving healthcare for people living with dementia* (Alzheimer's Disease International,

[13] Founded in 1948, the WHO is a United Nations (UN) agency with the mandate "to bring humans to the highest level of health possible" (World Perspective, 2015, online). It defines health as "a state of complete physical, mental and social well-being, and does not consist merely of an absence of disease or infirmity" (World Health Organization, 1948, p. 1).

[14] Founded in 1984, ADI is an international federation dedicated to recognizing the challenges of AD and other major NCDs, overseeing Alzheimer Societies around the world, including the *Alzheimer Society of Canada* (ASC). This organization "believes that the key to winning the fight against dementia lies in a unique combination of Global Solutions and local knowledge. As such, it works locally, by empowering Alzheimer's associations to promote and offer care and support for people with dementia and their carers, while working globally to focus attention on dementia" (Alzheimer's Disease International, 2017, online).

2016) presents six chapters of recommendations to improve the care and services of people living with AD and NCDs, complementing those of the WHO.

1.2.2 Policies adopted by Canadian provincial governments

The following steps were taken to identify Canadian provincial AD and NCD public policies in grey literature over the past two decades:

1) Internet search: (Table 1-5)

Table 1-5 – List of keywords used to identify action plans

Series	Keywords
1)	"Alzheimer's" AND "strategy" AND "nom de la province"
2)	"Dementia" AND "strategy" AND "nom de la province"
3)	"Alzheimer's" AND "action plan" AND "nom de la province"
4)	"Dementia" AND "action plan" AND "nom de la province"

2) Scientific articles: Two articles addressed the theme of public policy/action plans adopted in Canadian provinces (Edick *et al*., 2017; Morton-Chang *et al*., 2016).

3) Validation: Confirmation of a research expert in the field that the public policies identified were the most relevant.

Action plans from eight Canadian provinces [15] were selected: Alberta (Alberta Health, 2017), British Columbia (Ministry of Health of British Columbia, 2016), Manitoba (Manitoba Government, 2014), Newfoundland and Labrador (Health and Community Services of Newfoundland and Labrador, 2002a), Nova Scotia (Province of Nova Scotia, 2015a), Ontario (Ontario Government, 1999), Québec (Ministère de la Santé et des Services sociaux, 2009) and Saskatchewan (Saskatchewan, 2004) [16].

1.2.3 Analysis grids

We used analysis grids to show relevant information from selected documents (Appendix A for scientific articles, Appendix B for Alzheimer's plans). Scientific articles were identified by format, methodology and theoretical framework. Other sections of the grid highlight information on setting policy agendas for AD and NCDs, formulation, main orientation and implementation. The grid is based on concepts of the Howlett public policy analysis model (Howlett 2011, p. 37) (e.g., policy goals, policy means, policy ideas, policy actors, etc.). A subsection of the grid includes various public policy measures previously identified (e.g., health promotion/dementia risk reduction; dementia awareness and friendliness; improved diagnosis; home support; improved access to care, long-term homes and aids; improved care coordination and caregiver

[15] Action plans selected are in section 2.1 entitled *Emergence of a social problem and adoption of Alzheimer's policies*.

[16] An article presenting an analysis of action plans, including those adopted in Canadian provinces (Edick *et al*., 2017) was identified. We chose to analyze four Canadian action plans that were not included in the article by Edick *et al*. (2017): Alberta (Alberta Health, 2017), British Columbia (Ministry of Health of British Columbia, 2016), Nova Scotia (Province of Nova Scotia, 2015a) and Ontario (Ontario Government, 1999).

support; workforce education on dementia; increased research; implementation plans, etc.) (Edick *et al*., 2017, p. 33; World Health Organization, 2017, p. 8). Finally, we also used several key concepts on the theme of implementation of public policy (e.g., policy evaluation, accompanying changes, disparities in implementation, implementation barriers, positive and negative effects of politics).

2 Emergence of a social problem and adoption of Alzheimer's disease policies

Our study explores how AD and other major NCDs emerged as a social problem in OECD countries and Canada, and the adoption of public policy on the political agenda.

2.1 In OECD countries

The emergence of AD and NCDs as a social problem tends to be country-specific, but major historical movements transcend all OECD countries.

2.1.1 Dementia as a public policy priority

Discovered in the early 1900s by Dr. Alois Alzheimer (Tagarelli *et al*., 2006), the disease of the same name was of little social concern until the 1970s, and of little political interest before the 2000s, explaining why the period between 1900 and 1970 can be described as a no man's land for AD and other major NCDs (Ngatcha-Ribert, 2007). Indeed, before 1970, cognitive disorders were generally perceived as a near-normal result of the aging process (Ngatcha-Ribert, 2007). The first phase of support for people with AD and NCDs revolved around psychiatry and care of the sick in hospices, a strategy of guarding (Ngatcha-Ribert, 2007), or hiding patients from public view.

Geriatric interest in AD and NCDs emerged around 1985, transforming the logic of guarding-type care by promoting the idea that these diseases are not the result of normal aging, but rather a pathology with age as a major risk factor (Ngatcha-Ribert, 2007). This trend accelerated and by 1995 neurologists were taking a greater interest in the context of new therapeutic developments. Dissociating these diseases from normal aging and the development of techno-scientific medicine helped focus intervention on treatment and management (Ngatcha-Ribert, 2007). It also contributed to the emergence of the first associative movements and resulting increase in media attention (Chaufan *et al*., 2011; Ngatcha-Ribert, 2007).

The growth of medical knowledge and dissociation of AD and NCDs from normal aging provided the grounds for the associative movement to formalize its demands. In the early years of the movement the debate focused on the importance of developing new medications and treatments as well as the need to improve the services and living conditions of people living with these diseases (Chaufan *et al*., 2011). Focusing on the biomedical aspect seemed the better strategy for getting more visibility and funding (Chaufan *et al*., 2011). However, the focus on this aspect of the debate proved to inadvertently help draw attention to the social problem. (Chaufan *et al*., 2011; Innes & Manthorpe, 2013).

In this light, Innes & Manthorpe (2013) state that biomedical perspective is crucial for a better understanding of symptoms of AD and NCDs. Yet current lack of treatment makes it necessary to mobilize the social-psychological perspective, providing a wide

range of individual services for people living with functional repercussions, as well as the social-gerontological perspective, which focuses on social structures that influence individual experience (Innes & Manthorpe, 2013). Both perspectives should be balanced in public policy (Innes & Manthorpe, 2013; Lucas, 2011; Porock *et al*., 2015).

In recent years, the demands of the associative movement have shifted from a narrow biomedical focus to highlighting the inadequately addressed psychosocial needs of people living with AD and NCDs (Chaufan *et al*., 2011). Since the early 2000s, this latter perspective is gradually being adopted in public policy, an important stage in recognizing the psychosocial needs of people living with AD and NCDs. (Ngatcha-Ribert, 2007; Innes & Manthorpe, 2013).

At least 25 countries have adopted an action plan[17], indicative of the growing political concern (Rosow *et al*., 2011, Alzheimer's Disease International, 2018). At the subnational level, at least 38 of the 50 states in the United States (Arbogast, Welleford & Netting, 2017) and eight of the ten Canadian provinces [18] have also adopted plans.

Some governments have adopted successive action plans as circumstances and needs evolve. For example, France adopted four plans between 2001 and 2014 (Ankri, 2016). The first plan focused primarily on AD and NCD diagnosis by means of memory

[17] Countries that have adopted action plans: Australia, Austria, Chile, Costa Rica, Cuba, Czech Republic, Finland, France, Greece, Indonesia, Ireland, Israel, Italy, Japan, Luxembourg, Malta, Mexico, Netherlands, Norway, Puerto Rico, Slovenia, South Korea, Switzerland, United Kingdom and United States.

[18] Canadian provinces that have adopted action plans: Alberta, British Columbia, Manitoba, Newfoundland and Labrador, Nova Scotia, Ontario, Québec, Saskatchewan.

consultations, the second plan added an emphasis on medication and care to the first, the third plan targeted the implementation of devices to integrate services provided to users and finally, the fourth plan is aimed primarily at consolidating services and extending them to people with other neurodegenerative diseases (Ankri, 2016).

In the next section, we will focus on the formulation of action plans and, more specifically, the various actors involved in their development.

2.1.1 Actors in action plan design

Action plans are drafted by governments, associations, or partnerships between associations and governments (Arbogast, Welleford & Netting, 2017; Pot & Petrea, 2013; Rosow *et al.*, 2011). The WHO highlights the importance of government collaboration with various relevant parties (World Health Organization, 2017). For example, action plans usually involve several public institutions, requiring close coordination (Hoffman, 2014). Some researchers propose that involving people with Alzheimer's disease, their families, organizations that represent them, as well as professionals, results in action plans that better reflect local needs and secure a stronger commitment on the part of stakeholders (Alzheimer's Disease International & World Health Organization, 2012; Arbogast, Welleford & Netting, 2017; Banarjee, 2009; Fortinsky & Downs, 2014; Lucas, 2011; McCabe & Bradley, 2012, Pot & Petra, 2013). In addition to this, another article stresses the importance of involving actors

representing people with AD and NCDs with specific issues, such as intellectual disability to ensure plans consider their needs (Watchman *et al*., 2017).

Lucas (2011) also recognizes the contribution of people living with AD and organizations that defend their interests. But in emphasizing the importance of the participation and empowerment of these actors, some government may use these same principles to disengage from their responsibility to ensure that needs of those affected are taken into account (Lucas, 2011). She noted the importance of partnerships between the state, civil society and people affected. For example, co-constructing policies including government and advocacy groups, is a powerful lever for recognizing the needs and wishes of people affected by the policies (Lucas, 2011). The participation and empowerment of actors remains a fundamental principle, though governments must support the active engagement of civil society and people affected in the partnership approach.

Our study identified the following countries, where key stakeholders were consulted or actively involved in the formulation of action plans:

- *Australia*: Development was carried out by a working group composed of representatives of various levels of government. The group consulted various actors, including users, caregivers and professional organizations (Rosow *et al*., 2011).

- *England*: The working groups responsible for development each included a caregiver and at least one person with AD (McCabe & Bradley, 2012). The process resulted in two large waves of consultations, conducted in collaboration with the Department of Health and the Alzheimer Society (Banarjee, 2009; McCabe & Bradley, 2012). The first was held jointly with the Alzheimer Society before the plan was drafted and 3,000 people were consulted about their concerns. The Alzheimer Society distributed questionnaires to people with Alzheimer's disease and their loved ones (Banarjee, 2009). On the basis of this first consultation, a Department of Health working committee drafted a proposal document for the second phase of consultation. More than 600 actors, including groups of professionals, people with AD and their loved ones, offered written comment. In addition, more than 53 consultations involving 4,000 people were held across the country (Banarjee, 2009; Rosow *et al*., 2011). To ensure a broad representation of the population, consultation dissemination strategy also targeted groups living with specific issues related to AD and NCDs, including people with learning disabilities, minorities and those living in remote areas.

- *Scotland*: The AD and NCD action plan was formulated in collaboration with various key actors, including the community sector, people affected and their families (Pearson, 2017). In the Fife region, the personalized care movement involved users in the policymaking process (McCabe & Bradley, 2012). A long or short version of the proposed action plan was distributed to the public, serving as a basis for the consultation process (McCabe & Bradley, 2012). Strategically placed

posters targeted the people concerned. Organizers received written comment and held group interviews with a large number of stakeholders, including people with AD (McCabe & Bradley, 2012). These consultations led to changes to the action plan, such as facilitating the transportation of people affected and awareness campaigns to promote healthy lifestyle (McCabe & Bradley, 2012).

- *United States*: An advisory committee comprised of federal and state representatives with responsibility for gerontological records proposed target recommendations for an action plan. (Porock *et al*., 2015).

- *France*: The development of the first Alzheimer's Plan in 2001 included holding 186 forums which allowed the participation of 13,000 people (Rosow *et al*., 2011).

- *Ireland*: The formulation process of the plan may have given rise to consultation with key stakeholders and people affected; details are not provided (Cahill, 2010).

- *Italy*: Representatives from the Ministry of Health, surrounding regions, the National Institute of Health, and three national associations representing users collaborated on developing an action plan (Di Fiandra *et al*., 2015).

The above arrangements involve key stakeholders in varying degrees of participation. England and the Fife region of Scotland have developed strategies for high levels of participation, evidenced by the inclusion of people affected in working groups responsible for policy formulation, group interviews and efforts to reach populations

affected by AD and NCDs, including people living with more specific issues. Such a strategy for high level participation and inclusiveness requires the state's concrete support.

2.2 Canada

The Canadian political system is federal in nature, with 11 jurisdictions of authority divided between the federal government and the ten provincial governments. The areas of jurisdiction are autonomous as defined by the Canadian constitution (Constitutional Act of 1867), but this division of powers is complex as certain issues overlap the boundaries established by the constitutional guidelines (Pelletier, 2013). Provincial governments are responsible for AD and NCDs since they have jurisdiction over health systems (Pelletier, 2013), although a Supreme Court of Canada decision states that health, in its broadest sense, is a shared jurisdiction (Schneider v. The Queen, 1982, 2 SCR 112 to 142). For example, the Canadian government can influence the funding of AD research, support the development of best practices, and act on housing for people affected (Alzheimer's Disease International, 2016; Morton-Chang *et al*., 2016). The shared jurisdiction ensures that both levels of government are involved in the adoption of public policy.

2.2.1 Dementia as a public policy priority

The scientific literature does not accurately track the emergence of AD and NCDs as a social problem in Canada in the 20th century, although there is no reason to assume it is fundamentally different from that of OECD countries as previously discussed. Since the early 2000s, the Alzheimer Society of Canada has published multiple reports recognizing these diseases as a major social issue. The 2010 report entitled *Rising Tide: The Impact of Dementia on Canadian Society* (2010) explicitly calls on Canadian and provincial governments to develop action plans (2010). The Alzheimer Society collaborated with a member of the House of Commons in tabling legislation (Bill C-233) that led to the adoption of a national strategy for AD and NCDs (Simpson, 2016). Following the federal government's announcement in June 2017 that Bill C-233 had passed, the Alzheimer Society issued a press release celebrating the long-awaited announcement, noting its own involvement in the process (Alzheimer Society Canada, 2017).

Prior to the federal government's announcement, eight of Canada's ten provinces had already adopted action plans, beginning in 1999. Continuing the collaboration between levels of government will avoid potential duplication of policy actions (Simpson, 2016).

The adoption of a Canadian national strategy:

- In 2015, the Conservative Party member of the House of Commons, Rob Nicholson, made a commitment to the Alzheimer Society of Canada to introduce

a bill addressing AD and NCDs (Simpson 2016; Guse, 2016). He teamed up with the Liberal Party member, Rob Oliphant in 2016, to table Bill C-233, in 2016, for the development and implementation of a Canadian strategy in collaboration with provincial government representatives. The bill was adopted in 2017 as *An Act respecting a national strategy for Alzheimer's disease and other dementias*. This law required a conference be held in the 180 days following enactment, including political actors and others involved in AD and NCDs (e.g., researchers, organizations providing care, professionals, associations, etc.) to prepare the development of the national strategy. In addition, the Canadian Minister of Health was to appoint a committee of no more than fifteen people with expertise in public policy development, to advise and support the minister in carrying out this work (Bill C-233, 2017). The development of a national strategy is currently underway.

Adoption of provincial action plans:

- *Alberta*: The *Dementia Strategy and Action Plan* was first adopted in 2002 and renewed in 2017 (Alberta Health, 2017). The 2017 plan was analyzed in this study.

- *British Columbia*: The first plan, *Provincial Guide to Dementia Care,* was adopted in 2012 and renewed in 2016 (Ministry of Health of British Columbia, 2016). The 2016 plan was analyzed in this study.

- *Manitoba*: The first plan, *Framework for Alzheimer's Disease and Other Dementias,* was adopted in 2002 and renewed in 2014 (Manitoba Government, 2014). The 2014 plan was analyzed in this study.

- *New Brunswick*: An action plan is not available. In 2017, the Government of New Brunswick Council on Aging published a comprehensive strategy, *We Are All in This Together: An Aging Strategy for New Brunswick* (Province of New Brunswick, 2017). This report proposes a strategy to support family caregivers and improve care for people with AD, including timely diagnosis.

- *Newfoundland and Labrador*: Two documents were adopted in 2002. The first plan, *Provincial Strategy for Alzheimer Disease and Other Dementia* (Health and Community Services of Newfoundland and Labrador, 2002a) presents broad policy objectives; the second, *The Provincial Strategy for Alzheimer Disease and Other Dementias. A Plan of Action!* (Health and Community Services of Newfoundland and Labrador, 2002b) outlines actions with specific targets and actors involved in implementation. We analyzed both documents.

- *Nova Scotia*: Two documents was adopted in 2015. The first plan, *Towards Understanding: A Dementia Strategy* (Province of Nova Scotia, 2015a) presents strategy and objectives; the second, *Dementia Strategy Action Plan* (Province of Nova Scotia, 2015b) includes a monitoring grid to operationalize changes spanning a three-year period. We analyzed both documents.

- *Ontario* was the first province in Canada to adopt an action plan, in 1999, *Strategy for Alzheimer Disease and Related Dementias* (Ontario Government, 1999). Development of a new plan is currently underway (Ontario Government, 2016). A discussion paper was published in 2016 and consultation sessions obtained feedback from the public sector (Ontario Government, 2016). We analyzed the 1999 plan; the latest version is now unavailable.

- *Prince Edward Island*: According to the provincial Alzheimer Society, in 2015 and 2017 the government committed to adopting an action plan, but it is not yet available (Alzheimer Society, Prince Edward Island, 2018).

- *Québec*: The action plan adopted in 2009 is entitled *Meeting the Challenge of Alzheimer's Disease and Related Disorders. A Vision Focused on the Individual Humanism, and Excellence* (Ministère de la Santé et des Services sociaux, 2009).

- *Saskatchewan*: The plan, *A strategy for Alzheimer disease and related dementias,* was adopted in 2004 (Saskatchewan, 2004).

2.2.2 Actors in action plan design

We did not find scientific articles on actors who participated in drafting provincial action plans, except for a brief outline of the situation in Québec (Godard-Sebillotte, Vedel &

Bergman, 2016). Nevertheless, several action plans do provide some information on the formulation process, which we analyzed for an initial profile[19].

Development of action plans has always been driven by a Ministry of Health or Ministry of Seniors. Ministries formed the committees responsible for making recommendations or developing plans. Information in the plans indicates that Alzheimer Society representatives have been involved in most of them, serving as committee co-chairs (Newfoundland and Labrador, Nova Scotia), committee member (Québec), coordinator of action plan consultation process (Ontario), or other collaborative activity not explicitly stated (Alberta, British Columbia). The Manitoba plan does not indicate Alzheimer Society involvement.

All plans indicate that discussion included experts, stakeholders representing key organizations related to AD and NCDs, or people affected. However, we noted that at least five of the provinces had developed more formal consultation mechanisms:

- *Manitoba*: Consultation was conducted with caregivers and care/service providers in urban and rural areas to validate strategic orientations (Manitoba Government, 2014).

- *Newfoundland and Labrador*: The Alzheimer Society initially conducted a consultation to develop a draft proposal (Health and Community Services of Newfoundland and Labrador, 2002a).

[19] This information is not consistently detailed in the eight provincial plans, so some actors are likely not included.

- *Nova Scotia*: Several public consultations were held across the province with surveys posted online (Province of Nova Scotia, 2015a). Over 700 people participated, including people living with AD and NCDs, their families and professionals and underrepresented populations, "members of the Acadian, African Nova Scotian, Lesbians, Bisexual, Gay, Transgender and Intersex (LGBTI), Mi'kmaq and Immigrant Communities" (Province of Nova Scotia, 2015a, p.3).

- *Ontario*: Public consultation was set up to obtain comments on the draft strategy, resulting in feedback from 180 citizens (Ontario Government, 1999).

- *Saskatchewan*: Focus groups were conducted province-wide to obtain feedback from caregivers. The Alzheimer Society's annual conference held a focus group for professionals, and another was conducted with physicians on Telehealth. Fifteen focus groups involved 338 participants. People living with AD and NCDs and caregivers also participated in working groups (Saskatchewan, 2004).

The analysis of actors involved in formulating action plans for AD and NCDs revealed that Alzheimer Societies were actively involved in this process, and important mechanisms for consulting citizens were developed. The Nova Scotia consultation process appears to be the most ambitious because of the number of people consulted and the strategies used to reach underrepresented populations.

2.3 Key learnings of section 2

- Between 1900 and 1970, Alzheimer's disease (AD) and other major neuro-cognitive disorders (NCDs) were the subject of very few social and political concerns. The medicalization of these diseases and the rise of the associative movement during the years from 1970 to 2000, contributed to their recognition as a social problem. However, psychosocial needs were sparsely addressed until around the year 2000, when these diseases became part of the political agenda.

- Since the early 2000s, 27 national governments have adopted action plans for AD and NCDs, not to mention the plans adopted by subnational governments. For example, in Canada, eight of the ten Canadian provinces have adopted action plans. The province of Ontario was the first to adopt a plan, in 1999.

- In 2017, the Canadian government passed legislation requiring the adoption of a national strategy in this area. Sustained collaboration between the federal and provincial governments will be required to avoid potential duplication.

- Several scientific articles show that the participation of civil society facilitates the development of an action plan. Seeking out and recognizing the expertise of people living with AD and their families, enables the design of public policies that are better adapted to the needs of the people concerned.

3 Main action areas of Alzheimer's policies

In the report, *Global action plan on the public health response to dementia* (2017), the WHO proposes seven action areas as a guide to governments (World Health Organization, 2017). The areas are general and targets are meant to be adapted to territorial and population context of a jurisdiction, e.g., cultural particularities, health system characteristics, current AD public policy, and the political process (Arbogast, Welleford & Netting, 2017, Edick *et al*., 2017, Pot & Petrea, 2013). Effective adaptation is a major determinant of implementation success.

The first action area proposed by the WHO is **to recognize these diseases as a public health priority through the adoption of action plans**. The formulation of a plan is in itself an affirmation of the first action area. The remaining six policy guidelines are:

1) Dementia risk reduction
2) Dementia diagnosis, treatment, care and support
3) Dementia awareness and friendliness
4) Support for dementia carers
5) Information systems for dementia
6) Dementia research and innovation

(World Health Organization, 2017)

We analyzed the action plans identified by Edick *et al*. 2017 based on these six action areas, and delineated them according to the main measures. In subsections below, results are given for OECD countries and Canadian provinces.

3.1 Dementia risk reduction

Studies increasingly reveal that risk factors for AD and NCDs are related to lifestyle, "physical inactivity, obesity, unbalanced diet, tobacco use, harmful use of alcohol, diabetes mellitus and midlife hypertension […], social isolation, low educational attainment, cognitive inactivity and midlife depression" (WHO, 2017, p. 17). Acting on these risk factors could reduce disease prevalence (Alzheimer's Disease International, 2016; World Health Organization, 2017). The WHO has proposed linking action plans targeting disease to programs aimed at health promotion and healthy lifestyles, with training for professionals to increase public awareness (WHO, 2017).

3.1.1 OECD countries

The comparative study by Edick *et al*. (2017) reveals that four of the evaluated 16 national action plans address the theme of a healthy lifestyle and regular medical check-ups: Finland, New Zealand, Scotland and Taiwan (Table 3-2). Development of research to reduce the risk of developing AD and NCDs is included in Section 3.5, *Dementia research and innovation*.

3.1.2 Canada

Five provincial action plans contain measures to help reduce the risk of developing AD and NCDs: Alberta, British Columbia, Manitoba, Nova Scotia, Québec. The measures

include development of research programs on this theme, and public awareness campaigns to promote a healthy lifestyle.

3.2 Dementia diagnosis, treatment, care and support

Care and services for people living with AD and NCDs need to be improved and better coordinated across organizations, from diagnosis to end-of-life care. For example, a large proportion of people affected do not have a clear diagnosis, hindering care and services (Alzheimer's Disease International, 2016, World Health Organization, 2017). ADI and WHO have proposed development of better services from a biopsychosocial perspective with public action focused on patient care. This requires training for professionals in organizations providing care and services based on best practices (World Health Organization, 2017). Strengthening the capacity of primary care systems to identify people with AD symptoms, make referrals for specialized care, and provide follow-up have been important points in ADI and WHO reports for several years (Alzheimer's Disease International & World Health Organization, 2012; Alzheimer's Disease International, 2016; World Health Organization, 2017). As a valid alternative to specialized services providing diagnosis, ADI notes that interdisciplinary models utilizing primary care services for diagnosis are currently being developed and should be considered. Canada stands out in this respect, evidenced by Canadian clinical practice guidelines proposing that primary care play a greater role in diagnosis (Alzheimer's Disease International, 2016).

3.2.1 In OECD countries

The guideline, *Dementia diagnosis, treatment, care and support* is considered in nine subsections.

3.2.1.1 Diagnosis and follow up

Edick *et al*. (2017) reveals that 15 of the 16 national action plans address diagnosis: Australia, England, Finland, France, Ireland, Israel, Japan, Malta, New Zealand, Norway, Scotland, South Korea, Taiwan, United States and Wales (Table 3-1), a key element of AD and NCDs action plans, as confirmed by other comparative studies (Arbogast, Welleford & Netting, 2017, Nakanishi *et al*., 2015, Rosow *et al*. 2011). This component is ubiquitous, but may be expressed differently. In a study comparing seven action plans, most of them entailed primary care professionals who identified people with the disease and referred them to specialized services for diagnosis (e.g., France, England) (Nakanishi & Nakashima, 2014, Ankri, 2016, Rocher & Lavallart, 2009). Some projects stemming from action plans in England and Norway are models for both diagnosis and follow-up from primary care organizations (Engedel, 2010, Evans, 2014, Greaves & Jolley, 2010, Koch & Iliffe, 2011).

Diagnosis is considered necessary for follow-up adapted to the needs of people affected, but the approach is uneven. Some authors indicate that governments should put more emphasis on diagnosis and follow-up services (Boyle, 2010, Chaufan *et al*., 2011, Lucas,

2011). The Edick *et al*. (2017) study showed that four of 16 plans addressed the theme of increasing support and resources in the early stages of AD and NCDs (e.g., preparation for future challenges, communication of information on available services): Japan, Norway, United States and Wales (Table 3-1). In addition, seven of the plans proposed to educate people affected and their relatives, by increasing dissemination of information about AD and its evolution: England, Ireland, New Zealand, Norway, Switzerland, United States and Wales (Table 3-2) (Banarjee, 2010, Edick *et al*., 2017).

3.2.1.2 Care coordination

Edick *et al*. (2017) indicates that 14 of the 16 plans address the issue of coordination of services: Australia, England, Finland, France, Ireland, Israel, Malta, New Zealand, Norway, Scotland, Switzerland, Taiwan, United States and Wales (Table 3-1), targeting various organizations providing services. A second study more specifically addressed different care transitions, noting that many plans utilize care coordinators and advisors (Fortinsky & Downs, 2014). It is unclear whether the latter have the mandate to coordinate care throughout the evolution of illness, or are involved in transition only (Fortinsky & Downs, 2014).

In England, the action plan proposes dementia adviser services to link the partners of a local territory, transmit information to users and refer them to appropriate services (Clarke 2014, Evans 2014, Iliffe & Wilcock 2009). In the United States, the plan calls for the development and implementation of new models to coordinate services (Thornill

& Conant, 2018). In France, the third action plan (2008-2012), focuses on implementing an approach to integrate services, the *Maison pour l'Autonomie et l'Intégration des malades d'Alzheimer* (MAIA)[20]. The MAIA organization is a single point of access with a mandate to coordinate services for people with AD or other major NCDs (Nakanishi & Nakashima, 2014). It is not intended to replace current organization of the French health system, but to create a new structure to integrate care and services provided at the local level (Pimouguet *et al*., 2013). It relies on six mechanisms, tested and validated in a Québec study (Hébert et le groupe PRISMA, 2003):

1) A joint-governing board involving all stakeholders in the medical, social, administrative and environmental fields, at all levels of responsibility (national, regional, departmental, local and clinical;
2) Integrated entry point for standardizing access to available services;
3) Shared information system between medical and social services;
4) Case management for older people with complex needs;
5) Standardized multidimensional assessment tool shared and recognized by all organizations providing services;
6) Individualized service plan developed at patient entry point in the case management process.

(Pimouguet *et al*., 2013, p. 313).

[20] Currently called the *Méthode pour l'Autonomie et l'Intégration des malades d'Alzheimer*.

3.2.1.3 Home support

Edick *et al*. (2017) reveals that out of 16 plans, seven address the issue of home care for as long as possible for people affected: England, Finland, France, Norway, Scotland, South Korea and United States (Table 3-1), including adapted home physical environments and increasing services offered. In France, teams of home-based care providers maintain the autonomy of people affected and respond to disease-related behavioral issues (Ankri, 2016, Lustman, 2011, Rocher & Lavallart, 2009; Pimoughet *et al*., 2013). In Section 3.4, *Dementia Awareness and Friendliness*, transformative community actions include allowing people to live at home as long as possible.

3.2.1.4 Long-term care facilities

Edick *et al*. (2017) indicates that out of 16 plans, six address improving long-term care facilities: England, Ireland, Israel, Malta, Norway, South Korea and Switzerland (Table 3-1), by increasing the number of specialists, adapting physical environments in institutions and developing units dedicated to people with AD and NCDs (Di Fiandra *et al*., 2015; Edick *et al*., 2017).). In France, two types of units have been developed for users with significant or moderate behavioral symptoms. The units are better adapted to their needs and reduce the use of medication (Ankri, 2016, Lustman, 2011, Rocher & Lavallart, 2009).

In England, the plan proposes better staff training, and the regulation and assessment of quality of services offered in care homes (Banarjee, 2010). The Greaves & Jolley (2010) editorial notes that major institutional issues are the low salary of professionals and the high rate of staff turnover, a point of view not acknowledged in the English plan.

3.2.1.5 End-of-life and palliative care

Edick *et al*. (2017) notes that five of the 16 plans addresses improving end-of-life care: England, Finland, Israel, New Zealand and Scotland (Table 3-1). This includes planning end-of-life care and adapting it to the specific needs of people with AD and NCDs (Edick *et al*., 2017). In a second study, nine out of 14 plans addressed palliative care and/or end-of-life care: Australia, England, Finland, Japan, Northern Ireland, Scotland, South Korea, Sweden and Wales (Nakanishi *et al*., 2015), and included action plans not identified in the first study. This is likely because the Nakinishi *et al*. (2015) study includes palliative care in the broad sense of no further available treatment, while the Edick *et al*. (2017) study focused strictly on end-of-life care.

The Nakanishi *et al*., 2015 study specifically compared proposed actions, based on 11 recommendations by the European Association for Palliative Care[21] (EAPC). Most of the action plans covered several EAPC recommendations, even though the concept of

[21] Recommendations: 1) applicability of palliative care, 2) person-centered care, communication and shared decision- making, 3) setting care goals and advance planning, 4) continuity of care, 5) prognostication and timely recognition of dying, 6) avoiding overly aggressive, burden-some or futile treatment, 7) optimal treatment of symptoms and providing comfort, 8) psychosocial and spiritual support, 9) family care and involvement, 10) education of health care team, 11) societal and ethical issues (Nakanishi *et al*., 2015, p. 5).

palliative care was rarely clearly stated, and the application of these concepts covers the life span of people affected (e.g., person-centered care, communication and shared decision-making, continuity of care and family care involvement). Other aspects, particularly those concerning end-of-life care are rarely addressed (e.g., societal and ethical issues, psychosocial and spiritual support, prognostication and timely recognition of dying). The authors suggest the concept of palliative care is preferable in action plans as it encompasses comfort care before the terminal stage and is more comprehensive than end-of-life care (Nakanishi *et al*., 2015). Policymakers should consider the timing and appropriateness of palliative care for people with AD and NCDs.

3.2.1.1 Access to care

Edick *et al*. (2017) shows that 15 of the 16 plans address improved access to care: Australia, England, Finland, France, Ireland, Israel, Malta, New Zealand, Norway, Scotland, South Korea, Switzerland, Taiwan, United States and Wales (Table 3-1), including single gateway access, and improved access for specific populations, e.g., rural.

In a survey analyzing 79 national and subnational plans for access of care for specific populations, 27 referred to intellectual/learning and/or developmental disability (Watchman *et al*., 2017). People with intellectual disability, particularly those with Down syndrome, are more likely to develop neurocognitive disorders and experience unique issues. Plans addressing this population segment varies greatly, ranging from a

presentation of specificities (United States), to defined actions for people with intellectual disability (Norway, Scotland). Researchers note that countries with revised plans give increased importance to these people (Watchman *et al*., 2017).

A comparative analysis of US plans indicates that most of them target specific cultural populations based on the realities of individual states (Arbogast, Welleford & Netting, 2017). Some plans take into account rural populations, or people with an intellectual disability (Arbogast, Welleford & Netting, 2017). Norway's plan targets improved access for three populations: people who develop AD/NCD at a young age; people who speak minority languages; and, the Sami indigenous people (Engedal, 2015). French and Japanese plans also target people who develop these diseases at a young age (Arai, Arai & Mizuno, 2010, Lustman, 2011, Rocher & Lavallart, 2009).

English and Welsh plans do not sufficiently consider the needs of specific populations. The latter has little content on linguistic minorities or people with intellectual disabilities (Woods, 2010). One study noted that regions of England face major issues related to AD and NCDs (e.g., lack of specialized services, limited access, expensive transport), which were not touched on in the English action plan (McDonald & Heath, 2008). An editorial notes that various specific groups have received little attention (Greaves & Jolley, 2010), even though they must be taken into account to ensure consistent services and reduce barriers to access.

3.2.1.2 Professional training

Edick *et al*. (2017) shows that all 16 plans address professional training: Australia, England, Finland, France, Ireland, Israel, Japan, Malta, New Zealand, Norway, Scotland, South Korea, Switzerland, Taiwan, United States and Wales (Table 3-2). Other comparative studies note this measure is ubiquitous (Fortinsky & Downs, 2014, Rosow *et al*., 2011). Overall, the measures were to develop professional skills and address the needs of people affected (Edick *et al*., 2017), but they vary from country to country as do the professionals involved: clinicians in general (Banarjee, 2010, Iliffe & Wilcock, 2009, Greaves & Jolley, 2010, Pearson, 2017, Thornill & Conant, 2018); general practitioners (Arai, Arai & Mizuno, 2010; & Wilcock, 2009); health and social care staff (Engedal, 2015); new professional roles have been developed, such as case managers in France (Pimouguet *et al*. al., 2013).

3.2.1.3 Person-centred care

Edick *et al*. (2017) shows that seven of 16 plans address person-centered care: Australia, Japan, New Zealand, Norway, Scotland, Switzerland and Taiwan (Table 3), involving users in planning and care based on need. Another study observes that some plans focus on delaying transition of care (e.g., from home to housing), rather than facilitating it. (Fortinsky & Downs, 2014). Similarly, Boyle (2010) argues that the English action plan is intent on avoiding bed blocking, not on developing care. The opinions of people with cognitive symptoms were generally not considered, and their remaining capacities

discouraged, a diminished perspective of their right to self-determination (Boyle, 2010). Beyond the discourse, some action plan measures do not necessarily address person-centered care.

3.2.1.1 Technological aids

Edick *et al*. (2017) reveals that three of 16 plans address technological aids, namely France, Japan and Scotland (Table 3-2). This measure aims to provide people with AD with various aids to perform activities they could not otherwise do, or provide remote surveillance (Edick *et al*., 2017). Few action plans address this theme, in keeping with the fact we found no scientific articles on the topic.

3.2.2 Canada

The guideline, *Dementia diagnosis, treatment, care and support* is considered in seven subsections.

3.2.2.1 Diagnosis

Seven provincial action plans contain measures to improve the diagnosis of AD and NCDs: Alberta, British Columbia, Manitoba, Nova Scotia, Ontario, Québec, and Saskatchewan, a priority as in OECD countries. Four provinces indicate that diagnosis

should be done in primary care settings, often in collaboration with nurses, with support organizations providing specialized care for atypical cases (Alberta, Manitoba, Québec, Saskatchewan). Areas of responsibility are not clearly identified in the British Columbia, Nova Scotia, and Ontario plans, although two of these provinces provide primary health care training in AD diagnosis/clinical activity. The large number of Canadian provinces focusing on primary care settings for diagnosis distinguishes them from other OECD countries, where diagnosis is mainly oriented towards specialized services.

3.2.2.2 Care coordination

Six provincial plans contain measures to improve care coordination: Alberta, Manitoba, Newfoundland and Labrador, Nova Scotia, Ontario, Québec. Both Newfoundland and Labrador have measures to improve coordination among the various service providers along the continuum, but mechanisms to achieve this are unclear. The other four plans have the same objective, but with defined coordination mechanisms: reduce the number of transitions in the continuum of care (Alberta); set up a single electronic medical record (Alberta); implement a service integration model tested in Québec (PRISMA) and France (MAIA) (Manitoba); develop referral mechanisms between organizations (Ontario); set up AD pivot nurses in primary care settings (Québec), and consolidate case managers to coordinate services between various organizations at the more advanced stages of AD (Québec).

3.2.2.3 Long-term care facilities

Four provincial plans contain measures to improve long-term care facilities: British Columbia, Québec, Ontario, Saskatchewan. British Columbia's plan improves assessment of the behavioral and physical symptoms of AD, including inappropriate antipsychotic drug treatment. The Québec plan establishes a committee on long-term accommodation, ensuring patient prescriptions are relevant. Saskatchewan and Ontario plans call for adapting the physical environment of residences to the needs of people with AD.

3.2.2.1 End-of-life and palliative care

Five provincial plans contain measures to improve end-of-life care and/or palliative care: British Columbia, Manitoba, Nova Scotia, Québec, Saskatchewan. Measures are presented briefly, indicating the importance of developing palliative care in the end-of-life period. Only in Manitoba are the concepts of end-of-life care and palliative care used interchangeably.

3.2.2.2 Access to care for underrepresented populations

Three provincial plans contain general measures to improve accessibility for underrepresented populations: Manitoba, Nova Scotia, Québec. The Manitoba plan recognizes the importance of support and access to specialized diagnostic services in the

regions, while Nova Scotia respects the needs of underrepresented populations in the delivery of care and services. Despite province-wide consultation with groups of minority status, plan measures are not detailed. Québec's plan promotes greater openness to cultural and religious differences, particularly in end-of-life care, as it is an area of tension with clinicians. The Alberta plan notes, but does not concretely detail, specific issues concerning underrepresented populations (e.g., indigenous populations, people speaking minority languages, lesbian, gay and transgender, rural populations, people with developmental disabilities, etc.). Watchman *et al*. (2017) proposes that people with intellectual disability be considered, but such measures are not in any of the adopted plans.

3.2.2.3 Professional training

Eight provincial plans contain measures for professional training (Alberta, British Columbia, Manitoba, Newfoundland and Labrador, Nova Scotia, Ontario, Québec, Saskatchewan). The most frequent measures proposed are:

- General training for all professionals in the health and social services system (Alberta, British Columbia, Newfoundland and Labrador, Québec); professionals working in organizations providing primary care (Alberta, Manitoba, Nova Scotia, Ontario, Québec, Saskatchewan); professionals working in long-term care facilities (Ontario, Québec); and for support and personal care workers (Newfoundland and Labrador).

- Québec and Saskatchewan plans stand out in providing training on AD to facility managers. In Québec, training is extended to decision-makers and public servants.

- The Saskatchewan plan identifies specific training themes, including any form of elder abuse, and use of physical, chemical and environmental restraints.

- Several plans promote collaboration with academic institutions to increase AD and NCD content in professional training (British Columbia, Newfoundland and Labrador, Québec, Saskatchewan).

Professional training measures are consistent in provincial plans, as in those of OECD countries.

3.2.2.4 Technological aids

Only the Québec plan contains measures on technological aids and collaboration with experts from academic and private sectors to explore the intervention potential of home automation (e.g.: fall detectors, remote monitoring for biological parameters, wandering alert systems). Both the aids and their implementation are still in the exploratory stage.

3.3 Support for dementia carers

Caregivers generally have known the people in their care for several years, and have worked with them on a daily basis. Thus they are essential partners in developing

personalized care and services. Caregivers are susceptible to physical and psychological burnout, and economic overload (Alzheimer's Disease International, 2016, World Health Organization, 2017). The WHO has proposed training professionals to meet caregiver needs, involving caregivers in care planning, and developing care and services adapted to their needs (e.g., respite programs, programs on dealing with people with AD and NCDs) (World Health Organization, 2017).

3.3.1 OECD countries

Edick *et al*. (2017) reveals that ten out of 16 plans had measures to improve support for caregivers: England, France, Israel, Malta, New Zealand, Norway, Scotland, South Korea, Taiwan and United States (Table 3-1), including respite services and peer support programs. Japanese and US plans have proposed publication of a training guide for caregivers (Arai, Arai & Mizuno, 2010, XinQi, Ruijia & Simon, 2014). The French plan includes training for caregivers developed by the France Alzheimer Association (Lustman, 2011, Rocher & Lavallart, 2009), and calls for day care respite centers and other types of innovative respite, such as night care, sensory stimulation activities, art therapy, etc. (Lustman, 2011, Pimouguet *et al*., 2013, Rocher & Lavallart, 2009). The English plan proposes assessing and responding to the needs of families of people affected, such as provision of respite care (Banarjee, 2010, Boyle, 2010). Buswell, 2009).

3.3.2 In Canada

Eight provincial plans contain measures for supporting dementia caregivers: Alberta, British Columbia, Manitoba, Newfoundland and Labrador, Nova Scotia, Ontario, Québec, Saskatchewan. The most frequent measures are:

- Increase the intensity and variety of respite services adapted to caregivers (Alberta, British Columbia, Manitoba, Ontario, Québec, Saskatchewan);

- Identify, simplify, or enhance programs to positively influence the financial situation of caregivers (Alberta, Manitoba, Nova Scotia, Québec, Saskatchewan);

- Encourage the role of caregivers in clinical decisions (Manitoba, Québec);

- Adopt and develop tools to assess caregiver needs and level of stress, also taking into account clinical needs (Manitoba, Québec, Saskatchewan);

- Provide training for caregivers (Nova Scotia, Saskatchewan).

3.4 Dementia awareness and friendliness

Alzheimer's disease and NCDs are often poorly understood. This can limit professional consultation at the onset of symptoms and contribute to stigmatizing people affected (Alzheimer's Disease International, 2016, World Health Organization, 2017). The WHO proposes awareness campaigns adapted to local realities, sharing experiences of people affected, and transformation of physical environments to promote participation,

inclusion, autonomy and the dignity of people with AD and NCDs (Alzheimer's Disease International, 2016, World Health Organization, 2017).

3.4.1 OECD countries

3.4.1.1 Education and public awareness

Edick *et al*. (2017) reveals that 13 out of 16 plans utilize awareness programs to educate the public about AD and NCDs: Australia, England, Finland, France, Ireland, Israel, Japan, Malta, New Zealand, South Korea, Switzerland, Taiwan and United States (Table 3-2). Italy proposed public education (Di Fiandra *et al*., 2015) to reduce stigma and isolation of those affected, and promote discussion of symptoms with professionals (Banarjee, 2010, Di Fiandra *et al*. 2015; Greaves & Jolley, 2010; Edick *et al*., 2017; Engedal, 2015). Japan has focused intently on raising awareness and educating the population (Arai, Arai & Mizuno, 2010). The period of 2005-2015 was designated to increase understanding by means of organized educational activities and conferences.

3.4.1.2 Dementia capable, dementia friendly and/or dementia positive

Fourteen of the 16 plans address the community support theme: England, Finland, Ireland, Israel, Japan, Malta, New Zealand, Norway, Scotland, South Korea,

Switzerland, Taiwan, United States and Wales (Table 3-2), with measures to transform physical spaces and increase support for people living AD and NCDs (Edick *et al*., 2017). In the United Kingdom, tens of thousands of volunteers have been trained to support people affected in day-to-day activities, such as attending medical appointments or social visits (Morton-Chang *et al*. 2016). In Japan, the orange plan provides for the mobilization of 8 million dementia care friends, including "bank staff, grocery clerks, schoolchildren and younger older persons" (Morton-Chang *et al*., 2016, p. 25). These efforts create community awareness, understanding, inclusion of people affected, and provide social support.

Another study explores concepts that enable transformation and inclusiveness in societies (Shih-Yin & Lewis, 2015). The authors note that the concept of dementia capable is used in a US action plan, while the concept of dementia friendly is used in four plans (England, Malta, Northern Ireland and Scotland) (Shih-Yin & Lewis, 2015).

1) Dementia capable concept:

   - United States: Professional skills and services are oriented towards the needs of people affected, promoting inclusiveness (Shih -Yin & Lewis, 2015).

2) Dementia friendly concept:

   - England, Malta: Transformation of the physical and social environment to facilitate normalization and improve mobility (Shih-Yin & Lewis, 2015);

- Northern Ireland: Focus on the adaptation of physical environment in care homes (Shih-Yin & Lewis, 2015);

- Scotland: Focus of initial plan on the physical environment in hospitals; focus of the second on wider transformation to reduce stigma in communities (Shih-Yin & Lewis, 2015).

The first concept acts on the needs of people affected, to ultimately include them in society, while the second acts on communities and societies to achieve full participation (Shih-Yin & Lewis, 2015). Authors recommended the US government include the concept of dementia friendly to include research, education, urban planning, and community living. Chaufan *et al*., 2011 notes that the United States needs to act on environmental transformation rather than continuing its focus on treatment. Shih-Yin & Lewis (2015) propose adding the concept of dementia positivity to dementia capacity and dementia friendly (Shih-Yin & Lewis, 2015, p.242). The authors feel it could be an important complement, as it fully considers the experiences of people affected and their right to live a meaningful life (Shih-Yin & Lewis, 2015, p 241).

3.4.2 Canada

3.4.2.1 Education and public awareness

Eight provincial action plans include measures to raise public awareness of AD and NCDs: Alberta, British Columbia, Manitoba, Newfoundland and Labrador, Nova Scotia, Ontario, Québec, Saskatchewan, to reduce stigma and educate citizens, caregivers, etc. Manitoba's plan is unique in noting the legal and financial importance of end-of-life care planning. Ontario has concretely operationalized how its campaign will unfold and is providing funding to each of the 39 local Alzheimer Societies to hire a public education coordinator mandated to carry out awareness programs at the local level.

3.4.2.2 Dementia capable, dementia friendly and/or dementia positive

The concepts of dementia capable and dementia positive do not appear in provincial action plans, although four of them contain measures including the concept of dementia friendly (Alberta, British Columbia, Manitoba, Saskatchewan). Alberta focuses on improving the physical environment, transforming social structures, and providing care based on need. In British Columbia, the concept is related to residential care homes better adapted to needs. In Alberta, the concept of Age Friendly Communities is being used as a basis for developing dementia friendly communities.

3.5 Dementia research and innovation

Research is key in reducing disease prevalence and developing innovative practices to improve quality of life. The WHO proposes research on prevention, cure, improved diagnosis, treatment and care, accompanied by studies on development and use of new technologies. The areas of health and social sciences, and implementation research are implicated (Alzheimer's Disease International, 2016; World Health Organization, 2017).

3.5.1 In OECD countries

Edick *et al*. (2017) notes that 12 out of 16 plans promote increasing research efforts: Australia, Finland, France, Israel, Japan, Malta, Norway, Scotland, Switzerland, Taiwan, United States and Wales (Table 3-2), for development of best practices and curative treatment. Riggs (2001) and Stone (2001) explore the importance of collaboration of the scientific community and policymakers resulting in more informed decisions, e.g., research results that are accessible and practical for policymakers.

The English plan is broadly based, proposing research to identify and fill unmet needs (Banarjee, 2010). In Italy, the plan focuses on development of research programs to improve the care and quality of life of people living with AD and NCDs (Di Fiandra *et al*., 2015). These two areas are poorly funded in the United States, as research is mainly directed toward curative treatment and preventive strategy, perceived as the most effective approach (Egge, 2014). Researchers point to the importance of increased

government funding for social science research, ensuring a better balance with biomedical research (Chaufan *et al*., 2011, Porock *et al*., 2015; Yin & Lewis, 2015). The situation is similar in France. Fundamental research has been heavily funded and clinical research, although supported, is being consolidated. Social science research is still underdeveloped, despite discourse in this direction (Ankri, 2016).

3.5.2 Canada

Seven provincial action plans contain measures on dementia research and innovation: Alberta, British Columbia, Manitoba, Nova Scotia, Ontario, Québec, Saskatchewan, the most frequent being:

- Financial support for research in the areas of prevention, improvement of care and services, and development of curative treatments (Alberta, British Columbia, Newfoundland and Labrador, Ontario, Québec, Saskatchewan);

- Improved coordination of research efforts (Manitoba, Nova Scotia, Ontario, Québec, Saskatchewan);

- Innovation, program development, and ongoing evaluation of new practices (Alberta, Manitoba, Nova Scotia);

- Improved knowledge transfer of practices (Alberta, Québec);

3.6 Information systems for dementia

The WHO proposes that information systems collect relevant AD and NCD indicators to develop actions based on evidence and improve the trajectories of care and services, from prevention to end-of-life (World Health Organization, 2017).

3.6.1 In OECD countries and in Canada

Edick *et al*. (2017) reveals that three out of 16 national plans address data collection and information systems for dementia: France, Japan and Taiwan Table 3-2), including epidemiological indicators, to monitor the disease evolution and guide health system decisions. Information systems are a component of French, Italian and Japanese action plans (Rocher & Lavallart, 2009, Di Fiandra *et al*., 2015, Arai, Arai & Mizuno, 2010), but information is sparse. The remaining articles and Canadian provincial action plans do not address this undeveloped topic.

3.7 Synthesis of main areas section

The Edick *et al*. (2017) analysis tables cover 16 national action plans and measures developed[22].

Table 3-1 – Summary of proposed measures in action plans adopted in OECD countries

	Improved diagnosis/ assessments	Improved access to care	Improved care coordination and transitions	Person-centred care
National strategies				
Australia	✓	✓	✓	✓
England	✓	✓	✓	X
Finland	✓	✓	✓	X
France	✓	✓	✓	X
Ireland	✓	✓	✓	X
Israel	✓	✓	✓	X
Japan	✓	X	X	✓
Malta	✓	✓	✓	X
New Zealand	✓	✓	✓	✓
Norway	✓	✓	✓	✓
Scotland	✓	✓	✓	✓
South Korea	✓	✓	X	X
Switzerland	X	✓	✓	✓
Taiwan	✓	✓	✓	✓
United States	✓	✓	✓	X
Wales	✓	✓	✓	X

	Support for persons with dementia	Caregiver support	Housing/ home support	Improved long-term care
National strategies				
Australia	X	X	X	X
England	✓	✓	✓	✓
Finland	✓	X	✓	X
France	X	✓	✓	X
Ireland	✓	X	X	✓
Israel	✓	✓	X	✓
Japan	✓	X	X	X
Malta	✓	✓	X	✓
New Zealand	✓	✓	X	X
Norway	✓	✓	✓	✓
Scotland	✓	✓	✓	X
South Korea	✓	✓	✓	✓
Switzerland	✓	X	X	✓
Taiwan	✓	✓	X	X
United States	✓	✓	✓	X
Wales	✓	X	X	X

[22] The two tables in this subsection are taken from Edick et al. (2017); original format has been modified.

Table 3-2 – Summary of proposed measures in action plans adopted in OECD countries (continued)

	End-of-life care	Tech aids	Health promotion	Educate persons with dementia/ caregivers	Educating the general public on dementia
National strategies					
Australia	×	×	×	×	✓
England	✓	×	×	✓	✓
Finland	✓	×	✓	×	✓
France	×	✓	×	×	✓
Ireland	×	×	×	✓	✓
Israel	✓	×	×	×	✓
Japan	×	✓	×	×	✓
Malta	×	×	×	×	✓
New Zealand	✓	×	✓	✓	✓
Norway	×	×	×	✓	×
Scotland	✓	✓	✓	×	×
South Korea	×	×	×	×	✓
Switzerland	×	×	×	✓	✓
Taiwan	×	×	✓	×	✓
United States	×	×	×	✓	✓
Wales	×	×	×	✓	×

	Education of the workforce on dementia	Improved epidemiological surveillance	Increased research	Implementation plans
National strategies				
Australia	✓	×	✓	✓
England	✓	×	×	✓
Finland	✓	×	✓	✓
France	✓	✓	✓	×
Ireland	✓	×	×	×
Israel	✓	×	✓	✓
Japan	✓	✓	✓	×
Malta	✓	×	✓	✓
New Zealand	✓	×	×	×
Norway	✓	×	✓	×
Scotland	✓	×	✓	✓
South Korea	✓	×	×	×
Switzerland	✓	×	✓	×
Taiwan	✓	✓	✓	×
United States	✓	×	✓	×
Wales	✓	×	✓	✓

(Edick *et al*., 2017)

3.8 Key learnings of section 3

- The main areas of the various action plans are broadly convergent. The experience of other jurisdictions is very useful in inspiring interested governments to develop an action plan. Many experts and studies recommend that policymakers draw a portrait of the situation in their jurisdiction, and translate and operationalize the major normative orientations into concrete measures, adapted to their political, social, population and territorial realities.

- The measures in the action plans most widely promoted are diagnosis, workforce training, and access to care. Action in these three areas is an obvious prerequisite for implementing adapted follow-up care, yet follow-up is at times overlooked in these plans.

- Despite the fact that the psychosocial needs of people living with the repercussions of AD and NCDs are better recognized now than in the 20th century, some action plan measures focus on the cure and the biomedical model. In Canadian provincial action plans, the biopsychosocial aspects are generally well thought-out. The concepts of dementia capacity, dementia friendly and positive dementia are particularly interesting for a holistic approach that fully considers the needs of people living with these diseases.

4 Implementation of Alzheimer's disease policies

As previously noted the development of an action plan is in itself a determinant of its implementation. Targeted measures that take into account local population particularities, and active stakeholder involvement greatly facilitate implementation.

The WHO discusses the importance of providing sufficient and ongoing financial resources to implement proposed measures (World Health Organization, 2017). The availability of financial resources has clearly influenced the process in several countries, although guidance at the national level and the support of local actors are also important aspects that policymakers must take into account.

4.1 OECD countries

Following a brief look at the articles dealing with implementation of action plans, we will discuss three main determinants of effective implementation: adequate and well-distributed allocation of financial resources; establishment of a national steering committee; and, development of strategies to accompany change. The impact of action plans will be briefly touched on.

4.1.1 Putting into context articles focused on implementation

Of the articles analyzed in the literature review, only six focus on the implementation of action plans for AD and other major NCDs (Clarke *et al*., 2014, Haeffner-Cavaillon and al., 2015, Koch & Iliffe, 2011, Mukadam *et al*., 2014, Somme *et al*., 2014, Truswell, 2011), with most articles relating to cases in England and France. Other countries may have implemented measures, but we will address England and France.

Studies from some countries provide secondary information, covering implementation management or the financial resources deployed (Ankri, 2016, Bloch & Hénaut, 2014, Boyle, 2010, Buswell *et al*., 2009, Cahill, 2010, Egge, 2014, Fortinsky & Downs, 2014, Hoffman, 2014, Khachaturian, Khachaturian & Thies, 2012, Lustman, 2011, O'Connell, 2011, Peate, 2016, Pearson, 2017, Pimouguet *et al*., 2012, Porock *et al*., 2015, Pot & Petrea, 2013, Snyder *et al*., 2015, Rocher & Lavallart, 2009, Rosow *et al*., 2011, Thornill & Conant, 2018, Williamson, 2009, XinQi, Ruijia & Simon, 2014). The number of articles on implementation is currently limited due to the time lapse between the policy development, implementation and evaluation processes.

4.1.2 Adequate and well-distributed allocation of financial resources

The adoption and implementation of AD and NCD action plans generally result in the injection of new financial resources, however funding globally is often insufficient.

Some countries do not have adequate funds to implement proposed measures due in part to fiscal instability (Egge 2014, Hoffman 2014, O'Connell 2011, Peate 2016, Pot & Petrea 2013, Rosow *et al*., 2011, Williamson 2009). In the United Kingdom, researchers observe that staff involved in the implementation of new local services experience great uncertainly due to possible budget cuts in the health system (Clarke *et al*., 2014).

Financial resources in the United States are mainly focused on curative treatment, while action to improve care is underfunded (Porock *et al*., 2015, Thornill & Conant, 2018). Pearson (2017) mentions that budgets in Scotland are still too focused on crisis care, rather than avoiding it. Increased financial resources must be directed toward implementation with appropriate distribution for measures in the plan. New financial resources should be rigorously justified and specified in the implementation framework (Khachaturian, Khachaturian & Thies 2012).

The lack of financial resources to implement action plans is clearly significant in some countries, although it is important not to obscure other implementation issues that are not necessarily dependent on financial resources. We identified two important issues, namely a committee responsible for leading the implementation, and a strategy for implementing new practices.

4.1.3 Creation of a national steering committee for implementation

The implementation of an action plan involves many departments and multiple organizations at various levels of government. Dialogue between actors attached to these various institutions and organizations, in vertical and horizontal directions of governance, is necessary to accomplish the implementation of change (Egge, 2014, Hoffman, 2014). In Ireland, the action plan was adopted in 1999, but a committee was not appointed to ensure its implementation, explaining the limited progress in practice changes (Cahill, 2010, O'Connell, 2011).

Some countries have developed reporting and evaluating mechanisms to monitor implementation. In France for example, measures of the third action plan (2008-2012) were concretely operationalized and budgeted. The individual responsible for the file worked in collaboration with partners involved in the implementation (Rocher & Lavallart, 2009). Every six months, an assessment of progress was submitted to political authorities (Rocher & Lavallart, 2009). The mechanisms enabled close monitoring of the various measures on a continuous basis, and progress results were made available on a dedicated website (Lustman, 2011, Rocher & Lavallart, 2009). A formal evaluation was carried out when the plan ended, but results were not included in the article (Ankri, 2016).

United States law requires the federal action plan (2012) to be continually evaluated and updated annually, based on changing circumstances (Egge 2014, Hoffman 2014, Snyder

et al., 2015, Thornill & Conant, 2018, XinQi, Ruijia & Simon, 2014). The 2013 update enabled the development of new indicators to monitor progress and renewed efforts in key areas of research and services, promoting an ongoing evolution (Hoffman, 2014).

A strong and coordinated resolve at the national level appears necessary to achieve proposed change. Implementation of the English and French action plans also shows the importance of developing strategies that mobilize and support local actors to achieve the desired change.

4.1.4 Strategies for implementing new practices

Implementation of the English and French action plans led to pilot projects experimenting with measures to change professional practice. These projects are a viable strategy to experiment, learn from, and disseminate best practices on a larger scale.

4.1.4.1 England

The National Dementia Strategy implementation plan was not prescriptive (Rosow *et al*., 2011). Boyle (2010) adds that targets for change were not sufficiently specified and the measures implemented varied greatly by region. This may favour adaptation to local contexts (Koch & Iliffe, 2011), but a lack of framing can also lead to widening service gaps between regions and jeopardize the implementation of desired change (Boyle, 2010). For example, reducing the number of people living in care homes is a major

objective of the plan, yet there was scant increase in home and community care services during this period (Boyle, 2010). Similarly, the different evaluation and assessment tools used to determine AD and NCD diagnoses lack consistent markers, resulting in variations across the country (Koch & Iliffe, 2011).

The implementation plan of the National Dementia Strategy (2009) included two types of demonstration sites to experiment with new practices, and possible generalization on a larger scale:

1) *Demonstration site 1*: The site includes a Dementia Adviser (DA) and Peer Support Network (PSN). A DA sets up an organization with a mandate to identify services within a territory, refer users to services, and create links between organizations in local areas. Different types of support, such as legal assistance, are offered. A PSN develops support activities for those affected, including focus groups for people with AD or their loved ones (Clarke *et al*., 2014). A call went out for local actors to submit proposals for pilot projects; the department of health selected 40 sites (18 PSN projects and 22 DA projects) (Clarke *et al*., 2014).

   The national impetus for projects and the mobilization of local actors made it possible to link ministerial expectations with local needs (Clarke *et al*., 2014). Projects deal with local dynamics such as partnerships with other organizations, and involve people affected and their loved ones. This context helps define local needs and local services (Clarke *et al*., 2014). A demonstration site in one of the

most culturally diverse areas of London developed strategies to reach out and involve the black, minority ethnic, and refugee communities to define local projects and ensure accessibility to services offered (Trustwell, 2011).

The organizational aspects for these new services need to be retained, but with space for local actors to root changes in local and community dynamics. The support of actors is also necessary in situations where local implementation and agreement are difficult to achieve (Clarke *et al*., 2014). A National Dementia Strategy team was mandated to accompany the implementation of changes, but it was dissolved 18 months after the projects were launched (Clarke *et al*., 2014).

2) *Demonstration site 2*: Family physicians are responsible for identifying people with AD and NCD symptoms, although specialists are responsible for diagnosis. The National Dementia Strategy (2009) emphasizes assessment of potential new and innovative approaches to follow-up and diagnosis within primary care and secondary care (Iliffe & Wilcock, 2009, Koch & Iliffe, 2011). The government has proposed 40 demonstration sites to explore these new practices. Koch & Iliffe (2011) observed the practices of five family physicians working in innovative primary care organizations. A major challenge for these oganizations lies in the capacity of the department of health to adequately evaluate these models, determine best practices, and ultimately identify those that should be disseminated on a larger scale. (Koch & Iliffe, 2011). New models should be encouraged to emerge by mobilizing local clinical leaders, with changes in

practices properly evaluated and monitored to draw meaningful learnings (Iliffe & Wilcock, 2009, Koch & Iliffe, 2011).

On the basis of the English experience, we observed the importance of a balance between: 1) rooting experimental projects in local dynamics and context, particularly in terms of mobilization of local leaders, and 2) framing change and the support of local actors in the implementation. Valid evaluation mechanisms must be utilized in order to learn from these experiences.

4.1.4.2 France

In the context of France's third action plan (2008-2012), the MAIA organizational approach is central in implementing key recommendations to coordinate services. A MAIA is characterized by a combination top-down, bottom-up approach, and framed by specifications (Bloch & Hénaut, 2014). Local actors are mobilized to develop projects adapted to local conditions. Projects are subject to major parameters with innovation benchmarks, a process becoming common in health and social services areas (Bloch & Hénaut, 2014).

In 2009, 17 MAIA pilot projects were set up to test their relevance and the conditions favourable to generalization across France. An evaluation tool was utilized to learn from projects, but use was interrupted when research funds were cut following a change of government (Somme *et al*., 2014). As of 2011, an additional 40 MAIAs have been

developed in various regions, and over subsequent years the model has spread across France (Lustman, 2011, Pimouguet *et al*., 2013). The generalization phase evaluation was unlike the pilot project phase evaluation, in that it covered only some of the fundamental objectives that guided the development of the pilot projects. (Somme *et al*., 2014).

4.1.4.2.1 Key learnings from implementation strategies

Both England and France developed mechanisms to evaluate new practices and determine best practices before disseminating them on a national scale. These are promising strategies for governments to adopt; they establish strong evidence and promote change in progressive and incremental ways when implementing practice changes in health systems.

In light of these experiences, we suggest governments note four major aspects:

1) The mobilization of local actors is crucial in the implementing new practices, allowing change to be rooted in local realities (Bloch & Hénaut 2014, Trustwell 2011), and bringing local clinical leaders on board (Koch & Iliffe 2011). To achieve this, strategies must promote local actors in developing partnerships with other community actors, thus, rooting change in local needs.

2) Actors must be supported in implementing change in new and unestablished practices (Bloch & Hénaut, 2014, Koch & Iliffe, 2011). Changes that can be

expected must be globally tagged to avoid straying from or diverting basic policy objectives (Bloch & Hénaut, 2014, Boyle, 2010).

3) Projects must be rigorously evaluated to glean best practices and their implementation conditions (Iliffe & Wilcock, 2009, Koch & Iliffe, 2011, Somme *et al*., 2014). This aspect is essential for dissemination on a larger scale.

4) Dissemination of innovation, on a larger scale, must be carried out with strategies similar to the implementation of pilot projects. More research is needed to understand the capacity of governments to disseminate and sustain large scale innovative practices. The case of MAIA shows that in the expansion phase, some fundamental objectives of experimental projects may be abandoned (Somme *et al*., 2014).

The real and lasting effects of change are still poorly understood.

4.1.5 Presentation of general effects of these policies

The vast majority of articles reviewed focused on the anticipated effects of action plans rather than actual effects, as discussed in Section 3 (e.g., reducing associated stigma, improving quality of care, including care from the beginning stage to end-of-life, and increasing scientific knowledge). We identified two articles that measured the actual effects of action plans, in France and England, but it is important to emphasize that we

did not conduct a review of best practices in the field of AD and other NCDs, much less a meta-analysis of their effects.

1) The first article, published by a French research team, revealed that the increase in research funding following the adoption of the third Alzheimer's plan resulted in a significant increase in the number of publications on AD and NCDs (Haeffner-Cavaillon *et al*., 2015). A span of five years was observed between the increase of funds and increase in publications, with a longer period for clinical studies due to ethical and administrative issues (Haeffner-Cavaillon *et al*., 2015). Rather than creating a new research institute dedicated to AD and NCDs, new funding was utilized through existing research structures, explaining the rapid effect on publication (Haeffner-Cavaillon *et al*., 2015).

2) The second article, published by an English research team, examined the impact the adoption of the 2009 action plan had on the number of people diagnosed and the number of prescriptions to users (Mukadam *et al*., 2014). For three years preceding and following the adoption of the plan, researchers noted the evolution of the number of people diagnosed and the number of anti-dementia drug prescriptions (Mukadam *et al*., 2014). Both the number of people diagnosed and the number of anti-dementia drug prescriptions increased significantly following adoption of the plan (Mukadam *et al*., 2014). Researchers were unable to pinpoint the factors responsible. Three major measures may be involved: the increase of funding dedicated to diagnosis of AD, NCDs; name change of

organizations performing the diagnosis (e.g., from mental health services to memory clinics); and, national campaigns to destigmatize AD and NCDs (Mukadam *et al*., 2014). The first implementation measure could enable organizations to carry out more assessments and the last two measures could result in professionals and citizens being more receptive to diagnosis of these diseases (Mukadam *et al*., 2014).

We agree with the Fortinsky & Downs (2014) proposal that governments should lend more importance to the implementation and assessment of action plans, and most importantly, to the dissemination of results. Some governments have mechanisms to evaluate their plans, but little is known about their use, and study results of evaluations are not yet widely available in scientific literature.

In the short term, it would be valuable for researchers to review evaluations of action plans of OECD countries available in gray literature and examine the evaluation mechanisms. Such a study would make it possible to compare measures actually implemented in various countries, and gain insight into the conditions favouring implementation, organizations providing services, the effect on communities and the lives of people affected. To our knowledge, such a study has not been carried out.

There is also a lack of information on the implementation and assessment of Canadian provincial action plans, as discussed below.

4.2 Canada

The content regarding implementation of change in the provincial action plans varies greatly. We looked at eight provincial plans in terms of the key components identified in scientific papers: 1) allocation of financial resources, 2) national direction of implementation, and 3) implantation monitoring.

4.2.1 Allocation of financial resources

Our analysis of the plans did not reveal the amount of funding allocated by each province for implementation, apart from Ontario which specified $68.4 million over a five-year period. The amount allocated to each of the main targets is also specific (e.g., $1.1 million/year for staff education and training). This is in line with the Khachaturian & Thies (2012) proposal to justify and specify the use of financial resources in an implementation framework.

4.2.2 National piloting of the implementation

Three of the eight action plans mention the importance of coordinating provincial steering to implement changes: Alberta, Nova Scotia, Québec. Québec is the only province to identify potential barriers to change (e.g., involvement of an array of departments/ organizations, implication of several types of professionals, regional variation in population health and social characteristics, lack of a recognized practice

guide, etc.), and to propose a substantive strategy to circumvent the barriers (e.g., set up a ministerial team responsible for implementing and monitoring, develop regional plans adapted to population and health-related contexts, appoint a group of experts to draw up practice guidelines, etc.).

British Columbia and Newfoundland and Labrador do not propose a strategy for managing implementation, but the institutions responsible for ensuring implementation of each priority action are identified (e.g., particular ministry, government organization, community association, etc.).

4.2.3 Monitoring and evaluation of implantation

Monitoring is included in British Columbia, Alberta and Nova Scotia action plans. In British Columbia, a table shows the progress and status of actions targeted in the first plan (e.g., completed or in progress), and also shows actions to be developed. Québec has developed another type of monitoring plan for implementation (MSSS, 2012).

The Alberta and Nova Scotia plans specify the year in which various proposed actions will be rolled out, over a five-year period for Alberta, and a three-year period for Manitoba.

The Québec government has selected an independent research team to conduct a continuous evaluation of the implementation of changes, as part of experimental projects

to strengthen primary care (Godard-Sebillotte, Vedel & Bergman, 2016), before disseminating innovative practices across the province.

4.2.4 Area for future research

Some provinces have identified specific mechanisms to accompany and monitor the implementation of change (Alberta, British Columbia, Manitoba, Nova Scotia, Québec), while others have limited content (Ontario, Newfoundland and Labrador, Saskatchewan). Some provinces have also conducted implementation assessments, although few scientific articles have been published on this topic. As in OECD countries, we are aware of no comparative study of the evaluations of implemented provincial plans, an area for future research relevant to the Canadian scientific community and policymakers.

4.3 Key learnings of section 4

- Several scientific articles reveal that implementation of an action plan is greatly facilitated if the targeted actions are precise and well-embodied in the populational particularities of the jurisdiction, and if the various stakeholders are actively involved in the realization of these projects.

- Many governments have adopted action plans on AD and NCDs, in a context of national and international mobilization, although implementation varies widely. Scientific articles identify three major measures to facilitate the implementation of action plans: 1) allocation of sufficient financial resources that are well-distributed in the

action areas; 2) set up of a committee to pilot the implementation; and 3) development of implementation strategies to support changes in practice.

- Regarding implementation strategies, some governments have developed experimental projects to determine best practices and implementation conditions, followed by national dissemination of results. Scientific articles indicate four major aspects that policymakers need to take into account when undertaking this strategy: 1) the mobilization of local actors is crucial to root the changes in local realities; 2) the changes must be tagged and local actors must embody the fundamental objectives of public policy; 3) these experimental projects must be rigorously evaluated to draw meaningful learnings from them; and 4) the large-scale dissemination of innovative practices must mobilize the same implementation strategy and maintain the importance of the conceptual foundations on which the experimental projects were based.

- Two scientific articles have shown a positive influence resulting from the implementation of action plans. In England, the number of people diagnosed has increased significantly and in France, both diagnoses and the number of scientific publications have increased significantly. This makes it possible to precisely demonstrate that the anticipated effects of certain action plans translate into real effects.

- Several studies have compared the content of the action plans. To our knowledge, no study has compared the evaluation of plans between the countries of the Organization for Economic Cooperation and Development, or between Canadian provinces. Such a study would promote a better understanding of the types of evaluations mobilized by governments, the actual measures that were implemented, and the conditions which favoured their implementation.

Conclusion

This literature review report presents a snapshot of public policies for AD and other major NCDs in OECD countries as well as in Canadian provinces[23]. We have shown that the emergence of these diseases as a social and political problem, and consideration of psychosocial needs of people affected are relatively recent. These diseases have become public health priorities prompting some governments to adopt targeted action plans.

The public policies are globally coherent and act on related main areas. Ownership must, however, be achieved by the governments, whether they be national or provincial, so that the main normative orientations are operationalized in concrete measures, adapted to the cultural, socio-sanitary and political particularities of their jurisdictions. The real action will, however, be achieved only through the effective implementation of the measures promoted in the action plans, and therefore, governments must first address this important project. Only this commitment will improve the quality of life of people living with the repercussions of these diseases, and hopefully, one day, develop a treatment to cure them.

[23] This report focuses on Canadian provincial action plans and policy studies in OECD countries. The scope of the latter varies greatly from one study to another. The reader cannot infer that a measure announced in a plan has been implemented or had the expected effect.

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APPENDIX A: Analysis grid used for scientific articles

<table>
<tr><th colspan="4">Literature review / Alzheimer's policies
Analysis grid of scientific articles</th></tr>
<tr><td colspan="2">Reference :</td><td colspan="2">Country :</td></tr>
<tr><td colspan="2">Format
☐ Scientific article ☐ Master/thesis
☐ Research report ☐ Other</td><td colspan="2">Content
☐ Empirical ☐ Analysis of a policy
☐ Literature review ☐ Editorial</td></tr>
<tr><td colspan="4">Research question:</td></tr>
<tr><td colspan="4">1) Methodology and theoretical framework</td></tr>
<tr><td colspan="4">N :</td></tr>
<tr><td colspan="4">Collected data and analysis strategies :</td></tr>
<tr><td colspan="4">Theoretical frame :</td></tr>
<tr><td colspan="4">2) Recognition of the social problem</td></tr>
<tr><td rowspan="3">Emergence of the social problem</td><td>Dynamics of recognition of the social problem</td><td colspan="2"></td></tr>
<tr><td>Policy ideas</td><td colspan="2"></td></tr>
<tr><td>Persistent challenges to the recognition of these diseases</td><td colspan="2"></td></tr>
<tr><td colspan="4">3) Policy content and formulation</td></tr>
<tr><td rowspan="15">Main action areas of Alzheimer's policies
(policy goals & policy means)</td><td>Creation of new organizations</td><td colspan="2"></td></tr>
<tr><td>Risk reduction</td><td colspan="2"></td></tr>
<tr><td>Dementia awareness</td><td colspan="2"></td></tr>
<tr><td>Diagnosis and follow-up</td><td colspan="2"></td></tr>
<tr><td>Dementia friendly</td><td colspan="2"></td></tr>
<tr><td>Long-term care facilities</td><td colspan="2"></td></tr>
<tr><td>End-of-life and palliative care</td><td colspan="2"></td></tr>
<tr><td>Care coordination</td><td colspan="2"></td></tr>
<tr><td>Support for dementia caregivers</td><td colspan="2"></td></tr>
<tr><td>Role of patients</td><td colspan="2"></td></tr>
<tr><td>Underreprensented populations</td><td colspan="2"></td></tr>
<tr><td>Training of professionals</td><td colspan="2"></td></tr>
<tr><td>Guide and practice tools</td><td colspan="2"></td></tr>
<tr><td>Technological aids</td><td colspan="2"></td></tr>
<tr><td>Dementia research</td><td colspan="2"></td></tr>
<tr><td>Other measures</td><td colspan="2"></td></tr>
<tr><td>Facilitators to the formulation</td><td colspan="3"></td></tr>
<tr><td>Barriers to the formulation</td><td colspan="3"></td></tr>
</table>

4) Role of actors		
Actors	*Policymakers*	
	Managers (ministry)	
	Managers (organizations)	
	Clinicians	
	Community organizations	
	Business	
	Researchers	
	Patient and caregivers	
	Other actors	
5) Implementation and evaluation		
Evaluation of the policy		
Change management		
Adaptation to local context		
Disparities in implementation		
Differences with adopted policy		
Facilitators to implementation		
Barriers to implementation		
Positive effects of the policy		
Negative effects of the policy		
6) Reflection of the researcher doing the analysis		

APPENDIX B: Analysis grid used for Alzheimer's action plans

Literature review / Alzheimer's policies *Analysis grid of action plans*		
1) Contextual considerations and plan formulation		
Reference		
Province		
Drafting period		
Table of contents		
Actors who participated in the drafting		
Other		
2) Normative considerations		
Policy ideas		
Approaches and values (policy ideas)		
3) Policy content		
Main action areas of Alzheimer's policies *(policy goals & policy means)*	*Creation of new organizations*	
	Risk reduction	
	Dementia awareness	
	Diagnosis and follow-up	
	Dementia friendly	
	Long-term care facilities	
	End-of-life and palliative care	
	Care coordination	
	Support for dementia caregivers	
	Role of patients	
	Underreprensented populations	
	Training of professionals	
	Training of professionals	
	Technological aids	
	Dementia research	
	Other measures	
4) Implementation and evaluation		
Planning for implementation		
Evaluation mechanisms		
5) Reflection of the researcher doing the analysis		